# **Project Title**

Electronic Data Methods (EDM) Forum for Comparative Effectiveness Research: Second Phase

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# Organization

AcademyHealth

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# **Structured Abstract**

**Purpose:** The EDM Forum was created to advance the national dialogue on the infrastructure and methods of health services research and quality improvement using electronic health data (EHD). In its second phase, the project focused on driving rapid collaboration among stakeholders who create data, methods and evidence to shape the next generation of learning health systems.

**Scope:** Priority areas included: improving the transparency and reproducibility of PCOR and related methods; advancing understanding of best practices to govern the use of EHD; developing methods for delivery system science; understanding and improving EHR data quality; and using patient-reported outcomes in practice.

**Methods:** The project team leveraged an integrated model of convening, collaboration, and dissemination to produce high-quality analytic products that synthesize challenges and innovations; connect relevant research initiatives and stakeholder groups; and disseminate current research and news using diverse in-person and virtual dissemination channels.

**Results:** The team has engaged more than 4,000 stakeholders through participation in virtual and in-person meetings and as authors and reviewers of online resources. The EDM Forum has produced more than 400 high-quality deliverables over the course of the project. Notable products developed in the second phase include: *eGEMs*, a peer-reviewed open access journal; Concordium, a 2-day meeting on the strategic development and use of evidence for health system transformation; support of 14 collaborative methods projects, including CIELO, a web application for sharing health data analytics and code; and two Communities of Practice.

**Key Words:** electronic health data, analytic methods, clinical informatics, governance, learning health system

### **Purpose**

The EDM Forum facilitates learning and collaboration among researchers and other key stakeholders who are generating the data, methods, and evidence needed to build learning health systems that will improve patient care and outcomes. The EDM Forum drives rapid collaboration among researchers and diverse stakeholders who create data, methods, and evidence to shape the next generation of learning health systems.

To achieve the mentioned goals, AcademyHealth pursued the following three primary aims to advance the science and conduct of comparative effectiveness research, patient-centered outcomes research, and quality improvement, including patient safety:

- I. Engage and convene a broad and diverse group of experts and relevant stakeholders through in-person and virtual meetings to identify and prioritize the scientific, technical, organizational, clinical, legal, and ethical issues and challenges to conducting CER, PCOR, and QI using ECD; cultivate discussion of new ideas and potential solutions; and, discuss approaches to sustainability.
- II. Conduct collaborative methods projects that propose and, if feasible, test new solutions to further advance methods development and knowledge. These projects will foster collaboration through targeted efforts to build methods, informatics, and governance strategies that contribute to building learning health systems that are also "doing" systems capable of improving patient care and outcomes.
- III. **Create and disseminate timely, diverse, high-quality and useful products**, including meeting proceedings, research analyses, and recommendations that will be broadly promoted in a range of publications and venues, such as *eGEMs* the EDM Forum's premier online journal.

Another key focus of the project was to work with AHRQ and EDM Forum stakeholders to develop a viable sustainability plan for continued activities.

#### Scope

### Background and Context

In 2010, AcademyHealth received a three-year cooperative agreement from the Agency for Healthcare Research and Quality (AHRQ) through the American Recovery and Reinvestment Act (ARRA) of 2009 to develop the Electronic Data Methods (EDM) Forum, charged with advancing the national dialogue and developing the infrastructure and methods for collecting and analyzing prospective electronic health data (EHD) for comparative effectiveness research (CER), patient-centered outcomes research (PCOR), and quality improvement (QI). The initiative was originally scoped to support investigators conducting the Prospective Outcome Systems using Patient-specific Electronic data to Compare Tests and therapies (PROSPECT) studies, Scalable Distributed Research Networks (DRN) for CER, and Enhanced Registries for CER and QI, as well as assembling relevant stakeholders with an interest in addressing the infrastructure and methods challenges that have arisen in the context of these projects.

In collaboration with AHRQ, AcademyHealth rapidly developed the EDM Forum into a "marketplace of people and ideas" in order to advance thinking about how to build learning systems capable of improving patient care and outcomes. AcademyHealth's innovative approach to convening and environmental scanning; synthesis and meta-learning; translation; and dissemination and application (see **Figure 1**) nurtured a constructive dialogue among key stakeholders working in this space, many of whom had not previously collaborated in this way. This framing and approach to advancing the dialogue allowed the EDM Forum to successfully evolve into a unique learning community that worked closely with our partners at AHRQ and

other federal agencies, as well as scientific experts, providers, patients, and business and policy leaders. In this way, AcademyHealth developed a collaborative, team-based approach to synthesizing creative, comprehensive, and practical strategies that use ECD to improve patient care and outcomes.

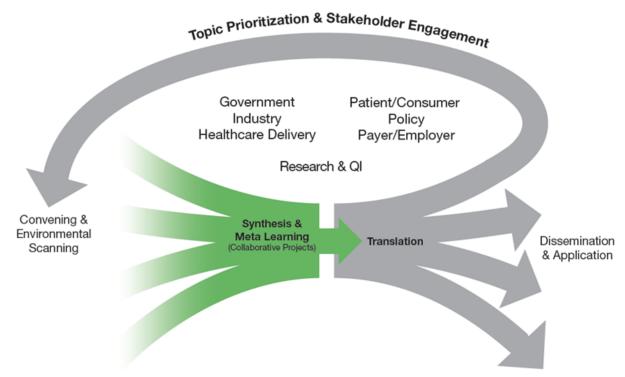


Figure 1. AcademyHealth's Innovative Approach to Directing the EDM Forum

In response to AHRQ's request for EDM Forum Phase II, AcademyHealth proposed core activities that maintained and enhanced relationships, engaged new perspectives, and provided opportunities to identify, prioritize, and resolve (when feasible) challenges to conducting comparative effectiveness research (CER), patient-centered outcomes research (PCOR), and quality improvement (QI) using EHD. Building on the strong foundation of AcademyHealth's prior relationships and work, the proposal for Phase II of the EDM Forum rested on strategies intended to deepen and broaden the impact of the EDM Forum. Thus, the goals of EDM Forum Phase II included ongoing engagement of the PROSPECT, DRN, and Enhanced Registry projects, as well as projects that are similar in scope; facilitating collaboration of stakeholders within the EDM Forum's domains; developing targeted collaborative methods projects to accelerate progress on strategic topics; and engaging more participants to facilitate a national dialogue on approaches to improve patient care and outcomes.

### **Participants**

The EDM Forum represents research projects and stakeholder groups that touch a wide range of research and care delivery settings, including primary care or ambulatory clinics, inpatient facilities, emergency departments, specialty clinics, academic medical centers, community health centers, long-term care facilities, and community households.

Stakeholder groups explicitly engaged for EDM Forum Phase II include healthcare delivery, patients / consumers, industry, business / payer, government, research / quality improvement, and non-profit / policy.

#### Methods

As a cooperative agreement, AcademyHealth continued to work closely with AHRQ to grow and expand the scope and membership of the EDM Forum. The following sections will detail the methods employed to meet the aims of the project, including study design, interventions, measures, and limitations for each aim, as applicable.

All methods and strategies were applied according to EDM Forum thematic domains of analytic methods, clinical informatics, governance, and the learning health system (as defined by AHRQ), in addition to seven stakeholder groups (healthcare delivery, patients / consumers, industry, business / payer, government, research / quality improvement, and non-profit / policy). Stakeholder groups were initially identified during Phase I of the EDM Forum based on a thorough review and synthesis of stakeholder groups developed for previous AcademyHealth projects. In Phase II, the groups were reviewed again by project consultants, the AHRQ project officer, and the EDM Forum steering committee to ensure we were targeting the right stakeholder groups and identifying appropriate organizations and experts within each group to engage.

I. Engaging and convening stakeholders to enhance understanding of the landscape of health research and QI

The project team utilized a number of convening and outreach strategies to bring together important, diverse perspectives and facilitate opportunities to provide guidance on EDM Forum activities, including:

- a. Regularly convening a Steering Committee to provide strategic leadership for the EDM Forum, particularly to prioritize topics and activities and identify stakeholders to engage in larger meetings and events.
- b. Hosting an annual stakeholder symposium for up to 200 stakeholders from various disciplines and sectors, including investigators from relevant projects, Steering Committee members, content experts, and representative organizations from stakeholder groups. The content of the meeting highlighted research, technical and non-technical challenges and promising innovations to build infrastructure for CER, PCOR, and QI, using EHD.
- c. Convening stakeholders for one in-person workshop per year on a special topic as agreed upon with AHRQ and with input from project advisors and the Steering Committee.
- d. Convening small to medium-sized workgroups or Communities of Practice that facilitate interaction of individuals around topic areas related to creating evidence, data, and methods to shape the next generation of health systems. Communities focus on activities under the following 'pillars' of action: sharing best practices on web-based calls and in person workshops; providing thought leadership through position papers; tackling shared challenges faced when using electronic health data, such as understanding and improving data quality when using electronic health records for research; and seeking formal funding and collaboration opportunities to promote sustainability, as appropriate.

In addition, the project team conducted regular stakeholder outreach to experts and organizations identified in collaboration with AHRQ, Steering Committee, and key advisors to understand current stakeholder needs and perceived gaps in current resources and dialogue, and identify new and emerging opportunities for collaboration with the EDM Forum, as well as

receive feedback on EDM Forum activities to date. Incubating collaboration and innovation through collaborative methods projects

II. Incubating collaboration and innovation through collaborative methods projects

AcademyHealth worked closely with AHRQ to develop the concept for collaborative methods projects that would provide more opportunities for investigators with different backgrounds and from diverse institutions to work together to create and test ideas and approaches. In each project year AcademyHealth launched a call for proposals and worked with the Steering Committee to review and select projects that would be innovative and useful to the EDM Forum community. All projects were required to address a critical issue in one of the thematic domains of the EDM Forum and identify and demonstrate collaboration.

### III. Accelerating translation and dissemination

AcademyHealth conducted various analyses, including peer-reviewed literature reports; site visit assessments of related electronic health data initiatives; stakeholder needs assessments; and *eGEMs* special issues. When possible, analyses were produced as an issue brief or white paper, or submitted to a peer-reviewed journal for broader dissemination.

The project team also leveraged a number of online dissemination vehicles to promote the high quality products produced for the EDM Forum, including the EDM Forum Community Portal website (<a href="www.edm-forum.org">www.edm-forum.org</a>), eRepository (<a href="repository.academyhealth.org">repository.academyhealth.org</a>), and eGEMs (<a href="www.egems.org">www.egems.org</a>); other social media including blogs, Twitter, Facebook, and LinkedIn; and an e-mail listserv and newsletter, the EDM Forum Monthly Update. On a regular basis AcademyHealth promoted new papers or issue briefs, calls for abstracts, funding opportunities, through relevant news sources.

#### Results

I. **Engaging and convening** stakeholders to enhance understanding of the landscape of health research and QI

#### Steering Committee

The Steering Committee engaged 26 experts from each of the seven stakeholder groups (see Appendix A for current membership). In the second phase, subcommittees were reconfigured to address key components and sustainability strategies for three areas, including: collaboration (six members), engagement (six members), and sustainability (ten members). The team also established an executive subcommittee comprised of the Steering Committee co-chairs, principal investigators, and AHRQ project officer. The executive subcommittee made final decisions on direction and content areas of the EDM Forum, with substantial input from the general Steering Committee members, subcommittees, and key advisors. The charge of each subcommittee was to: 1) provide input on priority topics for EDM Forum products; 2) identify potential authors or speakers; 3) review proposals from potential authors; and 4) review draft materials on an as-needed basis. Conference calls were held as needed.

Stakeholder Symposia and Special Topics Workshops

The project team held three large in-person symposia during the project period:

 Concordium 2016: Data and Knowledge Transforming Health, September 12-13, 2016, Crystal City, VA. Building on the success of Concordium 2015, this year's conference will brought together individuals and organizations working with health data to integrate evidence, practice, and policy in the delivery system setting. With discussion-based, innovative session formats, the conference is designed to be a transdisciplinary convergence of individuals designing and executing strategies for delivery system transformation.

- Concordium 2015: Data and Knowledge Transforming Health, September 21-22, 2015, Washington DC. Concordium 2015 brought together individuals and organizations working with big health data to integrate evidence, practice, and policy in the delivery system setting.
- June 2014: Stakeholder Symposium, June 7, 2014, San Diego. The 2014
   Symposium featured scientific experts, delivery system and policy leaders, and innovators who are building learning health systems of the future.

Collectively, these meetings engaged over five hundred experts in the fields of health data and delivery system transformation. The meetings showcased innovation and emerging science and promoted collaboration in an effort to improve health. As a part of the EDM Forum's sustainability strategy, the Concordium is being sustained as one of AcademyHealth's smaller annual meetings, with sponsorships

The project team, in consultation with AHRQ, also held one special topic workshop on Using Health IT to Advance the Use of Patient-Reported Outcomes in Practice, May 23, 2016, Washington, DC. Forty-one stakeholders, including AHRQ and AcademyHealth staff convened to discuss the current and future state of PROs and the potential for health IT to make an impact. Three breakout groups were assembled based around 1) opportunities to use new technology to promote the collection and use of PROs as well as patient generated data; 2) scale and spread use of PROs in practice, and 3) opportunities to collect and use PROs for individuals with multiple chronic conditions.

#### Communities of Practice

As mentioned, EDM Forum Communities of Practice were developed to facilitate interaction of individuals around topic areas related to creating evidence, data, and methods to shape the next generation of health systems. Communities focus on activities under the following 'pillars' of action:

- sharing best practices on web-based calls and in person workshops;
- providing thought leadership through position papers;
- tackling shared challenges faced when using electronic health data, such as understanding and improving data quality when using electronic health records for research; and
- seeking formal funding and collaboration opportunities to promote sustainability, as appropriate.

The project team established Communities of Practice around two topic areas: Data Analytics in Learning Health Systems (DALHS) and Population Health (PopCop). The DALHS Community of Practice supports the efforts of health systems and stakeholders who strive for continuous, embedded learning through ongoing generation and use of evidence-based information to improve the experience of care and the health of populations, and reduce per capita health care costs. A total of eleven members have been engaged in this work, regularly interacting on monthly web-enabled meetings, as well as in-person meetings adjunct to the Concordium and AcademyHealth's Annual Research Meeting. Visit <a href="http://www.edm-forum.org/collaborate/cop/dalhs">http://www.edm-forum.org/collaborate/cop/dalhs</a> to read more about DALHS members and their work, including

<u>forum.org/collaborate/cop/dalhs</u> to read more about DALHS members and their work, including production of seven peer-reviewed papers.

The PopCop addresses the shared opportunities and challenges of using electronic health data for public and population health. PopCop supports the efforts of local and state public health agencies to use and enhance the value of their data and improve the health of the populations

they serve. The PopCop meets virtually once a month to share opportunities and shared challenges to using electronic health data, as well as lessons learned and promising practices emerging in communities across the country. As opportunities and interest arise among members, the PopCop works together on writing, collaborative grant proposals, and collaborative projects. PopCop members advise the content, serve as reviewers, and participate in the annual AcademyHealth Concordium meeting. As a part of the EDM Forum's sustainability strategy, this group is now being actively sustained through other AcademyHealth work. Please visit <a href="http://www.edm-forum.org/edmforum/collaborate/cop/popcop">http://www.edm-forum.org/edmforum/collaborate/cop/popcop</a> to learn more about the group's activities, including seven relevant papers and resources produced out of this work.

### II. **Incubating collaboration** and innovation through collaborative methods projects

The EDM Forum also served as a test bed for the development of new tools and methods to increase collaboration and spread innovation. To date, the EDM Forum has incubated a total of 14 collaborative methods projects (see <a href="http://www.edm-forum.org/collaborate/collaborativeprojects">http://www.edm-forum.org/collaborate/collaborativeprojects</a>), two of which are being sustained beyond the project period.

The first is the Data Quality Collaborative, led by Dr. Michael Kahn (University of Colorado, Denver) brought together a group of leading experts to ensure that EHD is credible and high quality. The group had a special focus on comparative effectiveness research (CER) and patient-centered outcomes research. The collaborative published research ranging in focus from transparent reporting to engaging patients and consumers in data stewardship. The collaborative also worked to develop a tool to help standardize data quality checks and hosted a Code-a-Thon where teams competed to create visualizations of data quality results produced by the tool. In addition to this, the group worked to develop a comprehensive data quality assessment framework and guidelines, including draft recommendations that can guide the development of new analytic and reporting methods specifically directed to data quality assessment and reporting. Dr. Kahn and his colleagues have secured funding from PCORI to continue its important work.

Discussions with the EDM Forum Steering Committee and key advisors highlighted transparency and reproducibility of results as critical elements in cultivating a culture of collaboration in health research. Led by Dr. Philip Payne and his colleagues at The Ohio State University, the Collaborative Informatics Environment for Learning on Health Outcomes (CIELO) platform was developed to provide members of the research community with access to an opensource/-standards environment for data analysis and software sharing. Researchers can access each other's applications, contribute back their own, and build upon each other's contributions to extend or assemble modules in new analytical "pipelines." Initial launch of the beta environment yielded upload of twelve datasets and code collected from early adopters in the EDM Forum community. Projects on the platform range in focus from maternal health to interventions aimed at reducing health disparities – and all leave behind useful data sets and methods that can be adjusted or scaled to help others with similar interests. The project serves to support a broader goal of the EDM Forum to improve dissemination, transparency, and reproducibility of patient-centered outcomes research using EHD. Now at Washington University, St. Lois, Dr. Payne continues to work with the project team and has submitted three proposals for sustained funding, as well as a manuscript which has been accepted into the Journal for Medical Internet Research. Dr. Payne also presented CIELO during a panel at AcademyHealth's Datapalooza in May 2017. As a result of this presentation, the project team scheduled follow-up conversations with three potential partners to discuss synergies.

The Collaborative Methods Projects also yielded two living resources: the Governance Toolkit and the Patient Reported Outcomes (PRO) Toolkit. The purpose of the Governance Toolkit is to share and discuss resources related on governance of health information. Currently, the toolkit contains twelve tools, sample guidance documents, and practical approaches to common challenges are included, with the overall goal of advancing the national dialogue on governance issues of data and information for comparative effectiveness research (CER), patient-centered outcomes research (PCOR), and quality improvement (QI).

The purpose of the PROactive Toolkit is to foster open discussion and share resources related to the implementation of PROs in health care. The toolkit includes seven resources, including best practices, and a description of common challenges and recommendations. These tools are intended to assist clinicians, administrators and researchers who are interested in including PROs in their work. Areas of the toolkit address: how to make the case for PROs, how to include their collection in routine workflow, considerations for measure selection, what types of information technology may support PRO collection, and how to involve patients.

# III. Accelerating translation and dissemination.

As a part of the second phase, the project team in consultation with AHRQ and the EDM Forum Steering Committee redesigned and rebranded all of the EDM Forum's web and analytic products. The rebranded EDM Forum was intended to better articulate the value of participating in Forum activities, with the purpose of growing the community.

#### Website and Social Media

Staff continued redesigned the EDM Forum website (<a href="www.edm-forum.org">www.edm-forum.org</a>) and repository of products (<a href="http://repository.edm-forum.org">http://repository.edm-forum.org</a>). The launch of the rebrand as well as promotion of Concordium, engaged more stakeholders and ultimately grew the EDM Forum membership from 200 in 2010 to over 4,000 in 2017. In addition, the project used Twitter to promote Forum activities and products, ultimately amassing a Twitter following of over 1,000 people.

In the closing months of the project period and as part of sustainability planning, the project team migrated the analytic products housed on the repository to AcademyHealth's newly designed website. This move will continue to ensure a high level of visibility and promotion for EDM Forum work. In addition, the curation of relevant products is being sustained under additional AcademyHealth projects, including the Assistant Secretary for Planning and Evaluation's (ASPE) PCOR Resource Center directed by NORC at the University of Chicago and supported by AcademyHealth. EDM Forum products have also been leveraged and cross-promoted with the Community Health Peer Learning Program, an initiative directed by AcademyHealth and supported by the Office of the National Coordinator for Health Information Technology (ONC).

#### eGEMs

The creation of the open access journal, *eGEMs*, was a critical part of the project team's strategy to improve dissemination, transparency, and reproducibility of research using EHD. While researchers have always been able to share study results through existing peer-reviewed journals, the brilliance behind those results is often left in the shadows without a way for the community to disseminate the methods in sufficient detail to replicate and/or adapt them.

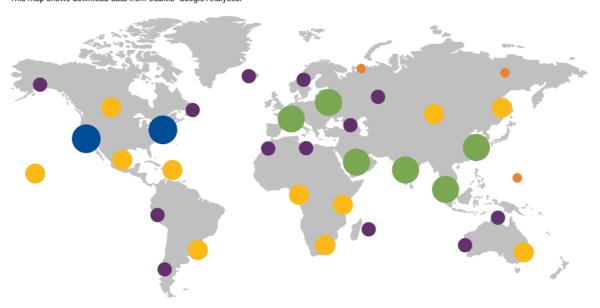
Launched in 2013, *eGEMs* has published more than 170 papers featuring cutting-edge work from leaders in the field and continues to be a premier journal for approaches to redesigning the health system. Publications include seven special supplements, two of which were externally supported. Published *eGEMs* manuscripts are indexed in PubMed Central and have amassed

over 160,000 cumulative downloads. Figure 2 is a map that showcases EDM Forum readership across the globe.

Figure 2. eGEMs Readership Map

# The Global Reach of eGEMs

Launched in 2013, *eGEMs* has published over 160 papers with more than 160,000 downloads from readers across the globe. This map shows download data from *eGEMs'* Google Analytics.



Much of *eGEMs* success is attributed to the expertise of its Editorial Board, which includes 26 thought leaders from across the country who serve as senior and associate editors. The project team regularly engaged the Editorial Board in quarterly meetings over the project period to discuss the scope and primary aims for the journal, priority topic areas, submission and review process, and metrics for success.

In December 2016, the AcademyHealth Board of Directors held their annual meeting and approved a proposal for AcademyHealth to retain *eGEMs* as a peer-reviewed, open access journal. Beginning in February 2017, the journal was sustained by a new business model, and led by an editorial board and appointed executive editor, Paul Wallace, M.D. Dr. Wallace served on the EDM Forum steering committee and is the former Senior Vice President and Director of the Center for Comparative Effectiveness Research at the Lewin Group, and current AcademyHealth senior scholar in residence. A national leader in population health research and the use of evidence to improve health care, Dr. Wallace was also an early advocate for the use of electronic health data for delivery system transformation.

With respect to sustainability beyond the project period, Dr. Wallace has overseen the development of a governance subcommittee to create a formal governance structure and bylaws for the journal. AcademyHealth's Board of Directors and the eGEMs Editorial Board also approved migrating to the Ubiquity Press platform to house *eGEMs* to enhance the submission and review process and to support the increasing volume of manuscripts. To support this transition, the editorial team has redesigned a business model for *eGEMs* based on sponsored special issues and modest article processing fees for authors. Published manuscripts continue to be open access and free for readers.

### Analytic Products

In total, over 400 analytic products have been produced in the EDM Forum. The project team has produced 18 analytic products under the EDM Forum in the form of issue briefs and peer-reviewed manuscripts. Twelve of these were produced during the project period. See Appendix B for a comprehensive list of EDM Forum products produced since 2010.

- EDM Forum Review. The EDM Forum Review was launched at the 2015 Concordium to highlight major events, initiatives, programs, and policies that set the stage for evidence-based system transformation. The 2015 Review (<a href="http://edmforum.review/2015/">http://edmforum.review/2015/</a>) and the 2016 Review (<a href="http://edmforum.review/">http://edmforum.review/</a>) featured key trends in the field, including the continued evolution of collaboration and open health science. Information for the report was gathered via stakeholder interviews, environmental scans, and literature reviews and synthesized into an online report.
- Site Visit Report. The site visits report synthesizes the perspectives of diverse stakeholders in communities engaged in cutting-edge work using electronic health data (e.g. PCOR researchers at academic medical centers; health embedded analysts; health department staff; safety net systems; Medicaid programs; the VA; and independent contractors). The report brings together perspectives on current progress using EHR data for PCOR, quality improvement, operational analytics, and population health, and will also illustrate where challenges persist with respect to bringing about a fully functioning learning health system. The EDM Forum team drafted the final site visit report in October 2016. (Appendix C)
- Literature Review Update. With permission from the AHRQ Project Officer, Ed Lomotan, the EDM Forum revised the scope of this analysis to demonstrate the impact of the EDM Forum. The final interactive report, featured a set of visualizations and graphics designed to 'tell the story' of the growth and impact of the EDM Forum network and associated activities. (See: <a href="http://www.academyhealth.org/files/735%20AH">http://www.academyhealth.org/files/735%20AH</a> EDM%20Report%202017 FINAL.pdf).

**Presentations at National Meetings and Conferences.** Staff identified opportunities to speak about the EDM Forum at several national meetings and conferences and elevated the visibility of our work. In the past year, the project team has made presentations at the following events:

- Health Data Innovator Privacy and Security Workshop, Wednesday, February 8: 11:30am-3:00pm, Biocom
- HCSRN Conference, San Diego, March 21-23 2017
- AMIA Joint Summits on Translational Science, San Francisco, Mar 27-30, 2017 (Dr. Margo Edmunds presenting)
- Health Datapalooza, Washington DC, April 27-28 2017 (Dr. Philip Payne presenting)

To date, staff have presented at over 30 national meetings and conferences to elevate the profile of the EDM Forum and identify key stakeholders that may benefit from this work.

### Discussion

For the past six years AcademyHealth has directed the EDM Forum with support from the Agency for Healthcare Research and Quality (AHRQ). With the support of AHRQ, the EDM Forum Steering Committee, and key advisors, the project team built new collaboration and dissemination products (Concordium, eGEMs, CIELO); grew a community of diverse stakeholders committed to sharing the best practices and lessons learned from conducting research using EHD; and cultivated high quality analytic products. All of these activities fostered

a collaborative learning environment that has now been modeled by similar projects (e.g. Community Health Peer Learning Program).

As is evidenced by the numerous sustainability strategies mentioned in this report, AcademyHealth is committed to building upon this community's work in using electronic health data (EHD) for health system transformation and has actively sought new sources of funding to continue support for key components of the EDM Forum. Significant progress has been made on sustaining the following initiatives:

- Communities of Practice. As mentioned, the PopCop is being managed by another project team at AcademyHealth. New funding has been sought to sustain group activities.
- eGEMs Special Issues. Staff have held discussions with nine federal and private funding entities who are interested in sponsoring a special issue in eGEMs. Staff also developed a special issue prospectus that includes information on cost of a special issue and roles and responsibilities of the sponsoring institution and guest editor.
- Concordium. AcademyHealth will continue to host Concordium and conduct outreach
  for sponsorship. We are actively identifying a partner to host the 2017 Concordium,
  which will be a smaller, invitation-only meeting.
- CIELO. The project team continues to have monthly meetings with Dr. Philip Payne to
  discuss sustainability strategies for CIELO. To increase visibility of the platform and its
  potential use, Dr. Payne presented at the 2017 Health Datapalooza in May 2017. As
  mentioned, the team's article on open science was recently accepted in the Journal of
  Medical Informatics Research (JMIR). The team will continue to meet with potential
  partners to scale the platform.

#### Conclusion

The Electronic Data Methods (EDM) Forum began as a way to connect 11 Agency for Healthcare Research and Quality (AHRQ) grantees working to improve the use of electronic health data (EHD) to improve health care. The grantees came together at a time of great change in health IT and were funded under the landmark American Recovery and Reinvestment Act (ARRA). This legislation incentivized the meaningful use of electronic health record technology and kicked off a race to harness the power of health data. While technology is about precision and detail, those who can see the big picture are the most effective overall.

AcademyHealth was chosen by AHRQ in 2010 to connect the ARRA-funded grantees in a dialogue around shared issues and challenges related to the rapidly evolving health care system. What followed over the next six years turned out to be much more than that. To date, the EDM Forum has become a community of over 4,000 strong, built on trust and mutual respect for diverse expertise, and committed to working together to solve some of the most pervasive issues in health care by viewing those issues as shared challenges. This community has brought together innovators on the front lines of health care from health care delivery systems and public health agencies; developed and shared recommendations before the most influential federal agencies; and led a national dialogue on critical issues such as governance, data sharing, methods and analytics, and dissemination of findings.

AcademyHealth cultivated and supported this community through a model aimed at fostering collaboration among leaders to generate pragmatic solutions. It began with small convenings to

identify shared challenges and grew to collaborative projects scoped to identify and, in some cases, implement solutions, all supported by creative dissemination methods and channels. Perhaps the most distinctive aspect of this community was its commitment to the common good. Participants were committed to improving the spread of innovation in a transparent and reproducible way. The group's solutions are documented in more than 400 freely accessible analytic products (e.g. issue briefs, reports, peer-reviewed manuscripts) and resources (e.g. webinars, toolkits), as well as in a peer-reviewed, open access journal created during the project.

### Significance & Impact

Through a model focused on bringing innovators together, supporting them in priority-setting and collaboration, and enabling them to disseminate their findings to a broad range of audiences, AcademyHealth's EDM Forum helped shape the next generation of learning health systems. Growing from a small group of individual projects to 4,000 engaged contributors, the EDM Forum has left a lasting mark on health care delivery systems research through hundreds of resources that will continue to serve the field for years to come.

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<sup>&</sup>lt;sup>i</sup> Holve E, Pittman P. A First Look at the Volume and Cost of Comparative Effectiveness Research in the United States. AcademyHealth. <a href="http://www.academyhealth.org/files/FileDownloads/AH\_Monograph\_09FINAL7.pdf">http://www.academyhealth.org/files/FileDownloads/AH\_Monograph\_09FINAL7.pdf</a>. Accessed November 27, 2013.